

## TESTIMONY IN SUPPORT OF HB 6645

### An Act Concerning Compassionate Aid in Dying for Terminally Ill Patients

Madame Chairs and Members of the Committee,

I'm Merrily Kaplan from Hamden. I'm here to offer my testimony in support of HB 6645, an act concerning compassionate aid in dying for terminally ill patients.

Today is my birthday and it is ten years and 13 days since my husband Steven Kahn ended his life. This is also Steven's testimony.

Steven had ALS, a devastating terminal illness. He fought hard, even participating in some experimental treatments to stay alive because he loved life and hoped by staying alive he might benefit from advances in stem cell or gene therapy. This was not to be so.

Steven was faced with the stark certainty of being locked into his body—without speech or movement—and desperately looked for help so that he could choose to end his life when he was ready.

At his, and our, time of great need and vulnerability, none of the doctors and caretakers he so trusted was ~~not~~ able or willing to help him with what he most needed and wanted: the assurance that he could have a measure of control and dignity. The primary care physician, neurologist, pulmonologist, therapists, hospice workers and social workers ALL caring professional people, could not meet him authentically. They were likely afraid, understandably so, that if they told my husband how or assisted him in any way, they could be called up by ethics boards and lose their licenses and/or go to prison.

After many disappointments and frustrations from the professionals we became aware of the Hemlock Society. There we found compassionate listening, a non-judgmental attitudes, useful information and support.

The terrible illness Steven endured, and I stood by watching, became a much worse experience because he had to make such a difficult decision in fear and secrecy, with the sense of shame that somehow gets engendered when you can't discuss something openly. It ate at the very limited reserves of energy left to him by the ravages of his illness and greatly increased his distress and anxiety.

Steven was well aware of Oregon's law which allowed compassionate aid in dying for terminally ill patients. Steven believed strongly that such a law should be a reality in his own state and he and I both knew his time would have been much eased had there been ONE.

To get a sense of the clarity of Steven's mind, his strong spirit, and his loving-kindness I have attached to this written testimony a copy of a letter he wrote to a close circle of his loved ones. If there is time I will read a few excerpts.

Thank you for your time and attention.

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> Hello Dad, Desmond, Margie, Anne, Bruce, David, Liza, Beckie, Kerry,  
 > Snow, Dave, Sylvia, Amy, Glenn, Josh, and Isabelle:

>

> I hope you are all well. I am writing to tell you that I have decided to  
 > end my life soon, by my own hand. I have made this decision, after much  
 > careful thought, on my own because it is the only way to avoid much more  
 > devastating suffering for myself and for Merrily. I am sorry if this is  
 > shocking or upsetting to you.

>

> We are now about to hire a part time aid to supplement the four hours of  
 > aid time we get from Medicare; but before long I will need full time  
 > professional care. Right now Merrily wakes up in the middle of the night  
 > and turns me; before long I will need more attention than she can give  
 > me at night. Eating is becoming very difficult because my right arm is  
 > weakening (the left is far worse than the right). Many other everyday  
 > activities are impossible or nearly so for me to do alone. As you know,  
 > it's precarious for me to stand, let alone take a step. I am severely  
 > fatigued all the time, and often intensely anxious. At times it's hard to  
 > open my left eye, and that will worsen. Worst of all, breathing is  
 > slowly becoming more difficult.

>

> It's not only these basic manual things that I can't do. I don't really  
 > have a creative life because creativity takes energy, and my energy  
 > level is so low I need to nap and rest constantly. I can't get out  
 > easily and participate in the world—it takes a caregiver and enormous  
 > amounts of time and preparation to do that. I become strangely anxious  
 > when anything fast moving or loud or bright or sudden happens. It's a  
 > process of shutting down, I think. I have stayed this long because I  
 > wanted to be sure there was no chance of arresting the progression of  
 > the disease, because I love seeing all of you and I love life. There is  
 > nothing very compelling that I can do, and life is becoming diminished  
 > day by day. With ALS, for me it's necessary to pick a point that is enough,  
 > because it's possible to be kept alive for years, locked in to a  
 > motionless body, unable to communicate in meaningful ways, and that is  
 > unacceptable to me.

>

> In fact I have had a fabulous life and done nearly everything I could  
 > want to do, gone nearly everywhere I could want to go, and had nearly as  
 > many wonderful people in my life as I could expect to have.

>  
> I see this as a way to end the violent carnage of my body by this  
> disease while I still have some quality in my life.  
>  
> I have found a way to end my life and prefer to do so alone or with  
> Merrily at my side if she wishes. It requires just a little strength and  
> dexterity, about the amount I still have. I may want friends nearby to  
> help guard for visitors and to help afterward with getting my body off  
> for nerve tissue donation for ALS research. I do not want anyone else to  
> be there. I feel that I have gotten to say goodbye to all of you in  
> recent months (save for Dave Gardner, so goodbye to you via Snowy), and  
> it's not necessary to have any of you there on the day I do this.  
>  
> I am writing you so that you will not have to wonder, and Mer won't have  
> the burden of explaining what happened or why. I'm not asking for your  
> approval, only that you honor my judgement.  
>  
> Every one of you has given me great gifts of caring and comfort and love  
> during this illness, and I have gotten more kindness and compassion from  
> friends than I could possibly have expected.  
>  
> Please respond and let me know you got this message.  
>  
> I love you,  
>  
> Steve